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A pilot, multicentre pragmatic randomised trial to explore the impact of carer skills training on carer and patient behaviours: Testing the cognitive interpersonal model in adolescent anorexia nervosa.

Short title: Carer skills training in anorexia nervosa

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### Trial Registration

ISRCTN83003225 - Expert Carers Helping Others (ECHO)

Declaration of interest: JT is a co- author of the book used in the carers' skills training intervention ECHO. JT, US, are co-authors of a clinician guide about including carers in the treatment of eating disorders. All receive royalties.

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## Abstract

**Aim.** To establish the acceptability, feasibility and approximate size of the effect of adding a carer intervention (Experienced Caregivers Helping Others (ECHO)) to treatment as usual (TAU) for adolescents with anorexia nervosa.

**Methods:** A pilot randomised trial comparing TAU (n=50) alone or TAU plus ECHO with (n=50) or without (n=49) telephone guidance. Effect sizes (ES) were regression coefficients standardised by baseline standard deviations of measure.

**Results:** Although engagement with ECHO was poor (only 36% of carers in the ECHO group read over 50% of the book), there were markers of intervention fidelity, in that caregivers in the ECHO group showed a moderate increase in carer skills (ES=0.4) at 12 months and a reduction in accommodating and enabling behaviour (AESED) at 6 months (ES=0.17). In terms of efficacy, in the ECHO group, carers spent less time care giving (ES= 0.40, p=0.04) at one year and patients had a minor advantage in body mass index (ES=0.17), fewer admissions, decreased peer problems (ES=-0.36) and more pro-social behaviours (ES = 0.53). The addition of telephone guidance to ECHO produced little additional benefit.

**Conclusions:** The provision of self management materials for carers to standard treatment for adolescent anorexia nervosa shows benefits for both carers and patients. This could be integrated as a form of early intervention in primary care.

## Keywords

Anorexia nervosa; eating disorders; carers; adolescent; family intervention; treatment; pragmatic randomised controlled trial; skills training; motivational interviewing



## Introduction

There is uncertainty about the management of anorexia nervosa (AN) because diversity in the clinical presentation, in terms of medical risk, age, duration of illness and psychosocial features, impacts on the response to treatment (J. Treasure, Stein, & Maguire, 2015). Many treatments are not grounded in theory and although there are many explanatory models few are used to shape treatment (Pennesi & Wade, 2016). We have followed the Medical Research Council (MRC) framework for developing complex interventions (Craig, *et al.*, 2008) by describing a cognitive interpersonal model for anorexia nervosa which includes both risk (emotional and cognitive style) and maintaining factors (the impact of starvation on brain, body and interpersonal function) (Schmidt & Treasure, 2006; J. Treasure & Schmidt, 2013). We have developed a variety of interventions based on the model (Schmidt, *et al.*, 2015; Schmidt, *et al.*, 2012; Schmidt, *et al.*, 2016). Those targeting the interpersonal element of the model have evolved into the Experienced Carers Helping Others (ECHO) skill sharing intervention (J. Treasure, Smith, & Crane, 2007). [ECHO](#) consists of three basic components (J. Treasure, Rhind, Macdonald, & Todd, 2015). First, there is a description of the model with information about the relevant risks and maintaining factors that impact on interpersonal function. This section also addresses carers' expressed need for information about the illness ([Graap, et al., 2008](#); [Haigh, 2003](#)). Second, the focus is on care giving behaviours which maintain the illness, such as high expressed emotion, accommodating, enabling, and a lack of congruence in caregiving styles (Salerno, Rhind, Hibbs, Micali, Schmidt, Gowers, Macdonald, Goddard, Todd, Lo Coco, *et al.*, 2016; Salerno, Rhind, Hibbs, Micali, Schmidt, Gowers, Macdonald, Goddard, Todd, Tchanturia, *et al.*, 2016; J. Treasure & Nazar, 2016). Third, ECHO teaches self-care, positive communication, and

compassion in order to maximise carer coping and model the skills needed for recovery and to support behaviour change.

ECHO has developed through a process of co-production with patients and carers. The intervention has been delivered in the form of carer workshops (Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008; Whitney, *et al.*, 2012) web materials (Grover, *et al.*, 2011), books and DVDs (R. Hibbs, Magill, *et al.*, 2015) Accommodating and enabling, expressed emotion and care-giving skills improve with these interventions (R. Hibbs, Rhind, *et al.*, 2015). A key question is whether patient outcomes also improve. One study found the addition of ECHO to support the carers of inpatients with anorexia nervosa was associated with fewer early discharges (R. Hibbs, Magill, *et al.*, 2015) and better patient outcomes two years following discharge (Magill, *et al.*, 2016). There have been no studies, which have examined the impact of ECHO on both carers and their offspring in adolescents.

Thus, the aim of this study is to examine the feasibility and acceptability of adding a carer intervention to treatment as usual (TAU) for patients with anorexia nervosa under the age 21. An additional aim was to estimate the size of improvements in both carer and patient wellbeing in order to plan a larger definitive trial. Our first hypothesis, which relates to the fidelity of the intervention, was that carers given the skills sharing materials (ECHO) would show more care giving skills and less accommodating and expressed emotion behaviours. Our second hypothesis related to effectiveness in terms of improved patient and carer outcomes. The third hypothesis relates to the “dosage” of the intervention and answers the question as to whether the addition of guidance adds benefit.

## **Method**



The protocol paper provides further details about the background and methodology (Rhind, Hibbs, *et al.*, 2014).

## **Design and Participants**

This is a multi-site, randomised controlled pilot study to examine the effectiveness of a carer skills intervention (Experienced Carers Helping Others (ECHO)) on the outcome of patients with AN (newly referred for specialist outpatient treatment for AN) below the age of 21, and their parents. A pragmatic design was used to test the effectiveness in everyday practice under flexible conditions with participants who were not highly selected.

Family participants (n=149) were recruited from 38 National Health Service (NHS) eating disorder outpatient services from across the UK. Of these, 17 were Child and Adolescent Mental Health Services (CAMHS), 13 were Specialist Adult Eating Disorder Clinics, and eight had both CAMHS and Adult teams recruiting (see acknowledgements). Northwick Park Hospitals Ethics Committee (11/H0725/4) approved the study, and it was adopted by the Clinical Research Network (<https://www.crn.nihr.ac.uk/>).

Inclusion criteria were as follows: 1) patients aged 13-20 years, 2) a primary diagnosis of AN or atypical AN (ICD-10 criteria). Upon meeting the aforementioned criteria, patients (step 1) and their carers (usually parents) (step 2) were offered the opportunity to participate in the study. Up to two carers per family could participate.

## **Procedure**

Following the two-step consent procedure, the clinical trial centre at the research hub (King's College London) randomised families: Treatment as usual (TAU) alone or TAU plus

Experienced Carers Helping Others (ECHO) materials (alone or with guidance) at a 1:1:1 ratio. Randomisation was stratified by study site (n=38), service type (Child & Adolescent or Adult Mental Health Services) and illness severity (BMI < 15kg/m<sup>2</sup> or weight-for-height percentage equivalent for < 16 year olds and/or presence of compensatory behaviours (vomiting). The research hub delivered the ECHO materials and guidance. The contributing clinical sites delivered TAU. Follow-up assessments (computerised self-report instruments and structured interviews for both carers and patients) were co-ordinated from the research hub. Researchers were blind to treatment.

## **Interventions**

### *Treatment as usual*

There is an expectation that NHS services follow the recommendations from the NICE guidelines (NICE, 2004) which for adolescents is to have treatment that involves the family. Inpatient treatment is a second line treatment, if there has been a failure to respond to outpatient care and/or if there are markers of high medical risk or problems with safety. An assumption in the study was that the recruitment sites would follow these standard care guidelines. However, we also obtained specific details of the treatment actually provided (to be reported later as part of the health economic analysis).

### *Experienced Carers Helping Others (ECHO) intervention.*

The ECHO materials (a book (J. Treasure, Smith, G., & Crane, A., 2007) and similar-content DVDs) were mailed to the carers. The details of ECHO have been published (Rhind, Hibbs, *et al.*, 2014) (J. Treasure, Rhind, *et al.*, 2015) and additional information is in the supplementary materials section. The carers in the guidance sub group of ECHO were offered ten 30-60-minute

telephone sessions. The sessions were divided between the main carers (i.e. both parents), if available. The people providing the guidance were, for the most part, people with a lived experience of caring for someone with an eating disorder. The others were post-graduate psychologists with minimal previous clinical training. In all, there were 18 guides. They were trained in the use of motivational interviewing and behaviour change principles (Abraham, 2012). The guides had regular supervision. The quality of the sessions were judged for competency in motivational interviewing skills and the majority were found to be adequate (Macdonald, *et al.*, 2014).

### **Assessment Measures**

Standard demographic variables (age, ethnicity, marital/living/employment status, years in education, contact time with relative) and some clinical information (illness duration, number of previous admissions, diagnosis, height, and weight) were obtained by self-report questionnaires developed for the study completed by both carer and patient as relevant. Both patients and their carers completed the eating disorder sections of the Development and Well-being Assessment (DAWBA) (Goodman, Ford, Richards, Gatward, & Meltzer, 2000), a computerised semi-structured interview, which generates DSM and ICD diagnostic predictions. A trained clinician (NM) reviewed the diagnoses. Patient diagnosis, number of previous admissions, height and weight information were validated by clinicians at the treatment site. Body Mass Index (BMI) and age, and gender-standardised weight-for-height percentage, were based on UK charts (Cole, 1995) where 100% wt./ht. is represented by the 50th wt. /ht. centile.

Participants (patients and carers) completed assessments at baseline and over the course of one year by telephone interview (blind to treatment allocation) and by self-report by post or email.

*Assessment measures (AN participants)*

- Clinical and demographic information (baseline).
- Short Evaluation of Eating Disorders (SEED) (Bauer, Winn, Schmidt, & Kordy, 2005). A brief, valid, reliable self-report measure assessing eating disorder symptoms over the past week. (Baseline and monthly for 1 year).
- Eating Disorders Section of the Development and Wellbeing Assessment (DAWBA) (Goodman, *et al.*, 2000). The eating disorders section of the DAWBA is a valid and reliable tool to detect eating disorder diagnoses in adolescents (House, Eisler, Simic, & Micali, 2008) (baseline, 1 year).
- Strengths and Difficulties Questionnaire (SDQ) (Goodman, 2001). An instrument to measure child and adolescent psychopathology with five sub scores (peer problems, pro-social difficulties, hyperactivity, emotional problems, and conduct problems) completed by informants in this case the primary carer (I = informants) and patients (SR = self-reports). (Baseline, 1 year).
- Clinical Impairment Assessment 3.0 (CIA (Bohn, *et al.*, 2008)). A scale measuring overall impairment on psychosocial functioning (baseline, 1 year).
- Depression, Stress and Anxiety Scale - short version (DASS-21) (Lovibond, 1993). A 21-item self-report measure (baseline, 1 year).
- The Client Service Receipt Inventory (CSRI); a well-established interview method of data collection, linked to cost analysis (J. Beecham, 1995; J. a. K. Beecham, M. (2001), in (ed.) s, Gaskell, 2nd edition, 200-224. , 2001) including use of specialist and generic health services, and education or employment (baseline, 6 months and 1 year).

*Assessment measures (carers)*

- Clinical and demographic information.
- Depression, Stress and Anxiety Scale (DASS-21) (Lovibond, 1993) see above for details (baseline, 1 year).
- The Family Questionnaire (FQ) (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002). A 20-item self-report measure of expressed emotion in carers. Items are rated on a 4-point Likert scale. (Baseline, 6 months).
- The Accommodation and Enabling Scale for Eating Disorders (AESED (Sepulveda, Kyriacou, & Treasure, 2009). A 33-item self-report measure. (Baseline, 6 months).
- The Caregiver Skills (CASK) scale (R. Hibbs, Rhind, *et al.*, 2015) A 27-item self-report measure of care giving behaviors to support eating disorder patients. (Baseline, 6 months and 1 year).
- Family eating patterns. Measure of attitudes to eating, weight or shape within the family and family eating patterns (baseline) (Neumark-Sztainer, Wall, Story, & Fulkerson, 2004) (baseline).
- The Client Service Receipt Inventory (CSRI). (J. Beecham, 1995; J. a. K. Beecham, M. (2001), in (ed.) s, Gaskell, 2nd edition, 200-224. , 2001) (As above). Additional expenses for the family because of AN (baseline, 6 months and 1 year) were also assessed.

## Statistical analyses

The main aim of this study was to estimate effect sizes and 95% confidence intervals (CI's) for key carer variables (carer skills, carer expressed emotion and enabling behaviours), patient eating disorder symptoms (SEED questionnaire and BMI), patient / carer distress and service use (as listed above). Further, we wished to establish how well carers engaged with treatment. To do this we recruited a relatively large sample for a pilot study at 149 patients, (TAU n=50, ECHO n=49, guided ECHO n=50). Outcomes were analysed at both 6 and 12 months post-randomisation with 2 treatment contrasts of interest (firstly, the group difference between the combined ECHO groups and treatment as usual (TAU) and secondly, between ECHO with guidance versus ECHO alone. For continuous outcomes (Carer skills, BMI), we assume the treatment contrast of interests is for two independent groups (t-test) and used the Bonferroni correction to p-values to allow for multiple comparisons. At 80% power and a p value of 0.025, firstly ECHO (n=99) vs TAU (n = 50) would allow us to detect moderate to large ES of 0.54 and an ES = 0.63 between guided ECHO (n=50) vs ECHO (n=49). Statistical analyses were based on the intent-to-treat principle, with participants analysed in the treatment arm in which they were randomised. R 3.2 and STATA 14 IC were used to carry out the statistical analysis. Missing data were imputed with the user written commands 'mi' and 'ice' in STATA (Royston, 2004).

All measures were continuous and so either linear regression or linear mixed models were used as described in the following. For patient outcomes, to estimate effect sizes (and 95% CI's) separate linear regression models were fitted for the six and 12-month outcomes. Explanatory variables included in the models were the treatment contrasts, baseline outcome score, and randomisation stratifiers (ED severity, age (child or adult), and site). As there could be more than one carer per patient, linear mixed models were used with random intercepts for each patient to

account for the within-patient correlation between carers. With the addition of this random effect, the fixed explanatory variables of the models for carers were the same as for patient outcomes. As some carers could have the same guide, the plausibility of including guide as a further random intercept was investigated. However, the data would not support the additional model complexity. Separate linear mixed models were fitted for six and 12-month outcomes. In addition to the effect sizes derived on the original scale, standardized ES's were estimated by dividing the mean differences between treatment-arms by the standard deviation of the outcome measured at baseline (pre-randomisation). To interpret effect size, the following convention was used: small 0 – 0.39, moderate 0.4 – 0.59 and large 0.6 – 1.

As there was a significant amount of missing data, we used a two-step process to allow data to be missing at random (MAR). Firstly, a binary indicator of missingness was generated for the SEED / BMI outcomes and then logistic regression examined associations between baseline variables and the post-randomisation variable, treatment completion. Any predictors of missingness (at a liberal  $p < 0.2$  criterion) were then included in multiple imputation by chained equations such that imputed values would reflect potential contributions from these variables without having to include these variables in the main analysis model. This allowed for a missing data generating process whereby identified baseline variables and treatment completion could drive missingness. Only psychiatric comorbidity was associated with missingness by this liberal criterion.

As indicated above, some patients had at least two carers and to allow the correlation between them to be included in the imputation model, they were included as separate outcomes. As some patients only had one carer, imputation for 'Carer 2' was conditional on their existence. One hundred imputations were generated and combined in the analysis models using Rubin's rules

(Rodwell, Lee, Romaniuk, & Carlin, 2014). For a limited range of variables, we allowed values to be imputed outside bounds to ensure correct coverage of confidence intervals.

## **Results**

### **Participant flow and Characteristics**

Figure 1 is the CONSORT diagram of the study. The rate of recruitment was slightly lower than anticipated and took 20 months. Of those 331 patients who were assessed for eligibility, 163 (49.2%) consented to be in the study. For the most part those who did not participate were uninterested in research. We failed to gain step 2 consent from carers of 14 of the eligible participants. Altogether 226 eligible carers also consented to participate and 149 families in total were randomised.

INSERT FIGURE 1

### **Demographic details**

As expected, the groups were well matched for both patients and carers in terms of most social demographic and clinical features, as shown in Table 1. *Patients*: The majority of patients were female (92%), white British (94%) with a mean age of 16.9 years (range: 13-21). Most were students and lived at home with their parents. The majority had over 21 hours/week of face-to-face contact with their primary carers and over a third had over 21 hours/week of face-to-face contact with their secondary carer. *Carers*: The majority of carers were female (mothers), married and in full time employment. Their mean age was 48 years (SD:  $\pm 5.2$ ). Eating/weight problems were present in over a quarter of caregivers and over a third had other self-reported



mental health problems. The median time spent caregiving (practical and emotional support) was 51 hrs. (range: 16-120 hrs. per /month).

INSERT TABLE 1 HERE

### *Clinical features*

The median age of onset was 14 years (range: 9-20). The mean duration of illness was 22 (SD:  $\pm 22$ ) months (longer than is usually seen in child and adolescent samples). At presentation, the mean weight for height (wt. /ht. %) was 82.9% (SD:  $\pm 11.2$ ) and BMI was 17.0 kgm<sup>2</sup> (SD:  $\pm 2.2$ ). The minimal BMI was 15.5 kgm<sup>2</sup> (SD:  $\pm 2.2$ ). Seventy-six percent had a diagnosis of AN and 24% atypical AN (see supplementary materials for further details).

The most common comorbidity was depression in 30%, obsessive-compulsive disorder (OCD) in 11%, and 4% had a possible/probable diagnosis of autism spectrum disorder (Rhind, Bonfioli, *et al.*, 2014). Approximately half of the sample reported no comorbidity. The level of comorbidity in the ECHO with guidance group was higher than in the other two groups (overall comorbidity: ECHO with guidance 56%, ECHO alone 43%, TAU 44%) and (depression: ECHO with guidance 42%, ECHO alone 20%, TAU 22%).

The majority of cases were recruited from child and adolescent services. Over 70% had no previous treatment, 10% had previous intensive day or inpatient care and 10% had two or more episodes of treatment. Eleven percent of the ECHO group and 20% of the TAU group had had previous family therapy.

### **Treatment engagement**

Forty percent (32/79) in the ECHO with guidance group and 32% (23/72) in the ECHO alone group had read over 50% of the book. Twenty-four percent (19/79) in the ECHO with guidance group and 21% (15/72) in the ECHO alone group watched over 50% of the DVD materials. A greater proportion of the carers of individuals with comorbidity (31%; 22/71) engaged with the materials than those without co-morbidity (23%; 18/78).

### **Carer outcomes:**

Summaries of carer variables over the period of the study are shown in Table 2a and results of the formal assessment of group differences are presented in Table 3. Overall loss to follow-up for carers was 23% at 12 months and differed little between groups.

INSERT TABLES 2 and 3 HERE

### **Between group carer outcome: ECHO (guidance and no guidance) compared with TAU.**

*Carer skills (CASK).* The ECHO group was estimated to have a higher level of carer skills at 12 months (standardised ES= 0.40;  $p=0.036$ ) with a smaller relative change at six months (ES 0.32,  $p=0.04$ ). *Accommodating and enabling behaviour (AESED).* There was a slightly greater estimated reduction in this behaviour in the ECHO group at six months. (Standardised ES= 0.19). *Expressed Emotion (FQ).* There was no difference in expressed emotion between groups (standardised ES= -0.04). *Time spent caregiving (TSI).* At 12 months' time spent caregiving was

estimated to be moderately lower in the ECHO group (standardised ES= 0.40,  $p=0.04$ ) with a smaller difference at six months (ES= 0.17). *Depression, Anxiety and stress (DASS)*. There was minimal estimated benefit for the ECHO group at 12 months (standardised ES= 0.07).

**Carer outcomes between ECHO groups: ECHO with guidance compared to ECHO alone.**

There was very little difference between the ECHO and ECHO guidance groups in carer outcomes (Table 3).

**Patient Outcomes:**

Summaries of patient variables over the period of the study are shown in Table 2b and results from the formal group comparisons are presented in Table 3. Overall loss to follow-up was 19% for patient outcomes.

INSERT FIGURE 2

***Between groups: ECHO (guidance and no guidance) compared with TAU***

*BMI*. There were small differences in BMI favouring ECHO at six (ES =0.18) and 12 months (ES= 0.17). *Weight for height (percentage wt. /ht.)*. There was a small advantage for ECHO at six months (standardised ES= 0.13) and at 12 months (ES= 0.13) over TAU. *Eating disorder psychopathology*. There were only small differences between ECHO and TAU in the eating psychopathology (SEED) measure (at six months (standardised ES= 0.07) and 12 months (ES= 0.26), the reduction favoured the TAU group). *Social function (SDQ pro-social, and peer difficulties)* There was a greater decrease in peer problems (SDQ) (Standardised ES= 0.36,  $p=0.027$ ) and a greater improvement in pro-social functioning (SDQ) (ES= 0.51,  $p=0.003$ ) in the

ECHO group. *General patient functioning (distress (DASS), clinical impairment (CIA)).* There was a minor advantage for TAU over ECHO at 6 months in DASS (standardised ES =0.19) and at 12 months in both DASS (ES =0.19) and CIA (ES= 0.18).

### **Patient outcomes between ECHO groups: ECHO with guidance compared to ECHO alone.**

*BMI:* BMI in ECHO without guidance was higher than ECHO with guidance at both six months (standardised ES= 0.44,  $p = 0.054$ ) and 12 months (ES= 0.35,  $p=0.13$ ). *Weight for height (percentage wt. /ht.).* Similarly, ECHO without guidance group had a moderate increase in weight for height at six months (ES 0.48,  $p=0.034$ ) and at 12 months (ES 0.37,  $p=0.089$ ), in comparison to the ECHO with guidance group. *Eating disorder psychopathology.* There was a small superiority in the reduction in psychopathology in the ECHO alone group (ES=0.28) at six months but the difference between the two forms of ECHO was less at 12 months (ES= 0.10). *Social function (SDQ pro-social, and peer difficulties):* ECHO with guidance showed a small benefit for peer problems (standardised ES= 0.13) but slightly less pro-social behaviour (ES = 0.21) than ECHO without. *General patient functioning (distress (DASS), clinical impairment (CIA)).* ECHO with guidance showed no benefits over ECHO without in both DASS (standardised ES= 0.1) and CIA (ES= 0.08) at 12 months

### **Additional Service Utilization**

A full cost-effectiveness analysis will follow but here we describe transfer to a higher intensity of treatment (in-patient or day care admissions). At 6 months, post-baseline total admissions to

higher intensity care were 19% (hospital 12% /day care 7%) in the ECHO group compared to 28% (hospital 16% / day care 12%) in the TAU group. Between 6-12 months, 10% of patients in the ECHO group were admitted (hospital 9%, day care 1%) and 10% of the TAU group (hospital 8%, day care 2%). There were no significant differences between groups.

The longitudinal changes in core variables (weight and eating psychopathology) over time are given in the supplementary materials.

## **Discussion**

This was a pilot pragmatic study to examine the feasibility, fidelity and acceptability of adding a carer intervention to treatment as usual (TAU) for patients, under the age 21, with AN and to estimate the potential size of improvements in both carer and patient wellbeing.

Only 36% of carers read more than 50% of the book and 20% watched more than 50% of the DVDs. Nevertheless, there was some evidence of fidelity to the intervention in that we found an increase in carer skills and a reduction in time spent caregiving at 12 months. However, there were negligible effects on accommodating behaviour, expressed emotion or carer distress.

In terms of effectiveness, there was a small superiority in weight related variables and fewer transfers to day or inpatient care within the first six months in the ECHO group. Patients from the ECHO group also had moderate sized improvements in interpersonal relationships (increased pro-social behaviours (SDQ) and fewer peer difficulties (SDQ)). However, there was no benefit in eating psychopathology and general distress.

In relationship to the “dosage” of the intervention adding telephone guidance to ECHO was associated with a marginal, improvement in engagement but this did not translate into an

advantage in terms of a change in carer or patient behaviours indeed there was an unexpected finding that patient outcomes in terms of weight were better in the ECHO alone group.

The low level of engagement with the intervention contrasts with a previous study giving the same materials to carers of people with anorexia nervosa undergoing inpatient treatment (R. M. Hibbs, N. ; Goddard, E. ; Rhind, E.; Raenker,S.; Macdonald, P.; Todd,G. ; Arcelus,J.; Morgan, J. ; Beecham, J.; Schmidt,U.; Landau, S.; Treasure, J., 2015) in which 68% of carers took up over 75% of their telephone sessions and read the carers guide (R. M. Hibbs, N. ; Goddard, E. ; Rhind, E.; Raenker,S.; Macdonald, P.; Todd,G. ; Arcelus,J.; Morgan, J. ; Beecham, J.; Schmidt,U.; Landau, S.; Treasure, J., 2015). Therefore it is perhaps not surprising that in this outpatient study, accommodating behaviours only fell by 16% whereas there was a 30% reduction in the inpatient carers (R. M. Hibbs, N. ; Goddard, E. ; Rhind, E.; Raenker,S.; Macdonald, P.; Todd,G. ; Arcelus,J.; Morgan, J. ; Beecham, J.; Schmidt,U.; Landau, S.; Treasure, J., 2015). In addition, time spent caring fell by 43% in the adolescent carers compared to the 68% reduction in the inpatient carers. In the early stage of adjustment, carers might not have the time or motivation to engage with the extra ECHO information. Carers of adolescents are usually actively involved in providing meal support whereas inpatient care provided respite from this task. Distress levels were 50% higher in carers of adolescent outpatients than in the carers of inpatients (R. M. Hibbs, N. ; Goddard, E. ; Rhind, E.; Raenker,S.; Macdonald, P.; Todd,G. ; Arcelus,J.; Morgan, J. ; Beecham, J.; Schmidt,U.; Landau, S.; Treasure, J., 2015) which may make it difficult to apply the ECHO materials in this format. Nevertheless there was positive feedback from carers and their offspring in the ECHO group (Macdonald, 2015).

A meta-synthesis of the experiences of carers of people with depression found that carers' adjustment and needs varied with the stage of illness. New carers experienced more stigma and responded with withdrawal and avoidance behaviours (Priestley & McPherson, 2016). A similar process may explain the low level of engagement in this sample.

An unexpected result was that the patients in the ECHO group with guidance i.e. a higher “dosage” of the intervention had less weight change. One possibility is that this surprising result might be attributed to a chance imbalance between the trial arms because the ECHO with guidance group had higher depression comorbidity at baseline.

This was a pragmatic design, representative of usual UK practice, which has strengths and limitations. The 2.4 kg<sup>2</sup> (95% CI. 1.2 to 3.7) increase in BMI at one year in the total sample is similar to that reported from the previous multicentre randomised study of adolescents (2.6 kgm<sup>-2</sup>) set in the UK (Gowers, *et al.*, 2010). In addition, the proportion of patients admitted to inpatient and day care was similar (Gowers, *et al.*, 2010). We were able to get core outcome data on a high proportion of participants and in addition, we used state of the art strategies to account for missing data. Although case mix and treatment given may have varied at each site, we controlled for this by stratifying the randomisation by centre.

In conclusion, we found only moderate uptake of the ECHO self-directed materials. Nevertheless, this was sufficient to produce changes in carers' behaviour as carers' skills improved, and accommodation and enabling decreased. We also found a reduction in time spent care giving. The patients had small improvements in weight and less transfer to inpatient care and their social functioning improved. Although adding guidance slightly improved the uptake

of the books and videos this did not translate into an increase in carers' skills nor a greater benefit for patients.

Although the size of effects was small, the ease of dissemination means that this could be a cost effect intervention particularly if the materials are offered at the time of first presentation in primary care or are more integrated into specialist care. These findings provide support for the cognitive interpersonal model as they show that by increasing carer givers skills it is possible to improve patient outcomes. The improvement in patient social skills suggests that there may be a specific benefit perhaps because of carers modelling high levels of interpersonal functioning.



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Table 1. Demographic and clinical characteristics of the sample.

	<b>ECHOg</b> n = 50	<b>ECHO</b> n = 49	<b>TAU</b> n = 50
<b>Demographics</b>			
Age (years): mean (sd)	16.7 (2.4)	17.2 (2.0)	16.9 (2.1)
Female: n (%)	44 (88%)	45 (92%)	48 (96%)
Ethnic origin: n (%)			
White (British, Irish, Other)	46 (92%)	47 (96%)	47 (96%)
Asian/Mixed/Other	4 (8%)	1 (2%)	3 (6%)
Missing	0 (0%)	1 (2%)	0 (0%)
Employment: n (%)			
Full-time employed	3 (6%)	1 (2%)	3 (6%)
Unemployed/homemaker/sick/retired/	2 (4%)	3 (6%)	2 (4%)
Student	44 (88%)	40 (80%)	41 (82%)
Missing	1 (2%)	5 (10%)	4 (8%)
Highest level of education: n (%)			
No qualification	20 (40%)	11 (22%)	18 (36%)
School	27 (54%)	37 (76%)	32 (64%)
University/other	1 (2%)	1 (2%)	0 (0%)
Missing	2 (4%)	0 (0%)	0 (0%)
<b>Clinical characteristics</b>			
Primary Diagnosis: n (%)			
Anorexia Nervosa	38 (76%)	33 (67%)	41 (82%)
Atypical anorexia nervosa	12 (24%)	16 (33%)	9 (18%)
BMI on admission (kg/m <sup>2</sup> ): mean (SD)	16.8 (2.3)	16.8 (2.4)	17.0 (2.3)
Illness duration (months): median	12 (3-84)	13 (2-110)	15 (2-108)
Currently receiving medication	23 (46%)	21 (43%)	15 (30%)
Previous Treatment: n (%)	17(44%)	14 (28.6%)	11 (22%)
Previous Treatment Type: n (%)			
Day patient care	5(10%)	3(6.5%)	7(14%)
Inpatient care	4(8%)	2(4.5%)	2 (4%)
Family therapy	2(9%)	9(18.4%)	10 (20%)
Co-morbidity: n (%)			
None	22 (44%)	28 (57%)	28 (56%)
Depression	21 (42%)	10 (20%)	11 (22%)
Anxiety related	4 (8%)	5 (10%)	3 (6%)
Other	3 (6%)	6 (12%)	8 (16%)
<b>Carers</b>	n = 78	n = 72	n = 76
<b>Demographics</b>			



Age (years): mean (SD)	49.1 (5.7)	47.7 (8.9)	47.8 (7.7)
Female: n (%)	51 (65%)	52 72(%)	52 (68%)
Ethnic origin: n (%)			
White (British, Irish, Other)	69 (88%)	68 (94%)	66 (87%)
Asian/Mixed/Other	6 (8%)	1 (1%)	6 (8%)
Missing	3 (4%)	3 (4%)	4 (5%)
Employment: n (%)			
Full-time employed	58 (74%)	51 (71%)	59 (78%)
Unemployed/homemaker/sick/retired/	19 (24%)	17 (24%)	11 (14%)
Student	1 (1%)	3 (4%)	3 (4%)
Missing	0 (0%)	1 (1%)	3 (4%)
Highest level of education: n (%)			
No qualification	1 (1%)	3 (4%)	2 (3%)
School	40 (51%)	50 (69%)	42 (55%)
University/other	36 (46%)	16 (22%)	29 (38%)
Missing	3 (4%)	1 (1%)	3 (4%)
Marital status: n (%)			
Married/living together	63 (80%)	50 (69%)	57 (76%)
In a relationship (not-cohabiting)	0 (0%)	0 (0%)	2 (3%)
Single/divorced/widowed/separated	14 (18%)	19 (26%)	13 (17%)

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**Table 2a. Carer Outcomes (by treatment group).**

N = 226	<b>ECHOg</b> n = 79	<b>ECHO</b> n = 72	<b>TAU</b> n = 75
Time spent caring (median, IQR)			
Baseline	45 (10.5-	62 (22.5-105)	51 (19.5-132)
Missing	14 (18%)	11 (19%)	7 (9%)
6 months	29 (10-70)	30 (4-85)	31 (6-90)
Missing	16 (20%)	14 (19%)	13 (17%)
12 months	12 (2-41)	12 (0-50)	19 (3.5-90)
Missing	19 (24%)	18 (25%)	16 (21%)
DASS: mean (SD)			
Baseline	30.5 (25.9)	30.3 (22.4)	27.4 (20.0)
Missing	2 (3%)	5 (7%)	3 (4%)
12 months	27.9 (21.7)	28.9 (25.2)	29.7 (27.9)
Missing	21 (27%)	16 (22%)	18 (24%)
AESED: mean (SD)			
Baseline	45.4 (21.1)	54.6 (21.6)	49.3 (22.3)
Missing	10 (13%)	7 (10%)	6 (8%)
6 months	39.2 (18.4)	45.8 (24.6)	45.6 (24.0)
Missing	22 (28%)	16 (22%)	23 (31%)
FQ: mean (SD)			
Baseline	47.9 (9.2)	47.8 (10.3)	47.2 (9.1)
Missing	3 (4%)	3 (4%)	3 (4%)
6 months	47.3 (9.0)	49.2 (10.1)	46.8 (9.0)
Missing	22 (28%)	17 (28%)	23 (31%)
CASK: mean (SD)			
Baseline	174 (34.7)	178 (39.7)	179 (35.6)
Missing	8 (10%)	14 (20%)	12 (16%)
6 months	190 (33.6)	184 (31.1)	185 (38.1)
Missing	21 (27%)	17 (24%)	22 (29%)
12 months	194 (39.3)	195 (38.2)	189 (40.3)
Missing	22 (28%)	16 (22%)	19 (25%)

Abbreviations: TAU – Treatment as Usual; ECHO – Echo intervention; ECHOg – ECHO Intervention with guidance coaching; DASS – Depression, Anxiety and Stress Scale; AESED – Accommodation and Enabling Scale for Eating Disorders; EE - FQ – Expressed Emotion Family Quotient; CASK – Carer Skills.

**Table 2b. Patient Outcomes (by treatment group).**

	<b>ECHOg</b> n = 50	<b>ECHO</b> n = 49	<b>TAU</b> n = 50
<b>BMI: mean (SD)</b>			
Baseline	17.0 (2.4)	16.9 (2.7)	17.3 (2.1)
Missing	0 (0%)	0 (0%)	0 (0%)
6 months	17.8 (2.4)	19.0 (2.6)	18.7 (2.6)
Missing	11 (22%)	7 (14%)	8 (16%)
12 months	18.3 (2.2)	19.4 (2.6)	18.7 (2.6)
Missing	9 (18%)	6 (12%)	13 (26%)
<b>% wt./ht: mean (SD)</b>			
Baseline	82.6 (11.2)	81.0 (12.3)	83.9 (10.4)
Missing	6 (12%)	3 (6%)	4 (8%)
6 months	85.5 (12.0)	90.3 (14.2)	88.3 (12.9)
Missing	14 (28%)	9 (18%)	12 (24%)
12 months	87.1 (11.1)	91.2 (13.1)	88.6 (13.1)
Missing	11 (22%)	7 (14%)	13 (26%)
<b>SEED – AN: mean (SD)</b>			
Baseline	1.83 (0.63)	1.86 (0.60)	1.90 (0.55)
Missing	2 (4%)	2 (4%)	1 (2%)
6 months	1.52 (0.69)	1.38 (0.77)	1.41 (0.76)
Missing	19 (38%)	14 (28%)	18 (36%)
12 months	1.44 (0.66)	1.32 (0.56)	1.33 (0.75)
Missing	18 (36%)	13 (26%)	19 (38%)
<b>DASS: mean (SD)</b>			
Baseline	62.8 (31.7)	61.8 (30.1)	71.4 (30.2)
Missing	0 (0%)	0 (0%)	1 (2%)
6 months	54.7 (23.9)	65.8 (33.3)	64.5 (30.5)
Missing	19 (38%)	15 (31%)	23 (46%)
12 months	47.8 (29.8)	51.9 (33.4)	52.8 (33.2)
Missing	13 (26%)	8 (16%)	18 (36%)
<b>SDQ– Peer Problems: mean (SD)</b>			
Baseline	2.8 (2.3)	3.3 (2.2)	2.8 (2.2)
Missing	7 (14%)	8 (16%)	11 (22%)

12 months	1.8 (1.7)	2.6 (2.0)	2.8 (2.2)
Missing	19 (38%)	9 (18%)	15 (30%)

SDQ– Prosocial Behaviour: mean (SD)

Baseline	7.6 (2.1)	6.4 (2.6)	7.5 (2.1)
Missing	7 (14%)	8 (16%)	11 (22%)
12 months	7.6 (2.0)	7.5 (2.1)	6.8 (2.2)
Missing	19 (38%)	9 (18%)	15 (30%)

CIA: mean (SD)

Baseline	29.8 (10.1)	30.8 (11.9)	30.9 (11.8)
Missing	1 (2%)	0 (0%)	1 (2%)
12 months	20.3 (14.4)	23.3 (14.4)	21.8 (13.7)
Missing	13 (26%)	9 (18%)	18 (36%)

Abbreviations: TAU – Treatment as Usual; ECHO – Echo intervention; ECHOg – Echo Intervention with guidance ; SEED (AN) - Short Evaluation of Eating Disorders (Anorexia Nervosa), BMI - Body Mass Index; % *wt./ht.* - Age adjusted weight for height; DASS – Depression, Stress and Anxiety Scale; CIA – Clinical Impairment Assessment ;SDQ - Strengths and Difficulties Questionnaire.

**Table 3. Estimated outcome differences for carers and patients between treatment arms (combined ECHO vs TAU or ECHOc, ECHO and TAU) at 6 and 12 months treatment post-randomisation.**

Carer Outcomes		6 months			12 months		
		Mean group difference (95% CI)	Test	Standardised Coefficient <sup>‡</sup> (ES)	Mean group difference (95% CI)	Test	Standardised Coefficient <sup>‡</sup> (ES)
<b>CASK</b>	Overall ECHO vs TAU	8.34 (-0.32, 17.0)	t = 1.89 p = 0.059	0.23	11.2 (0.00, 22.4)	t = 1.96 p = 0.05	0.31
	ECHOg vs Echo	3.15 (-7.06, 13.4)	t = 0.61 p = 0.545	0.09	0.15 (-13.5, 13.9)	t = 0.02 p = 0.98	0.00
	(log) Time spent caring	0.26 (-0.28, 0.80)	t = -0.95 p = 0.34	0.17	-0.63 (-1.24, -0.02)	t = -2.02 p = 0.044	-0.40 <sup>‡</sup>
<b>(log) Direct Spending</b>	Overall ECHO vs TAU	0.35 (-0.28, 0.98)	t = 1.08 p = 0.28	0.22	0.03 (-0.79, 0.85)	t = 0.08 p = 0.94	0.02 <sup>‡</sup>
	ECHOg vs Echo	-0.21 (-1.22, 0.80)	t = -0.41 p = 0.68	-0.07	-0.22 (-1.79, 1.35)	t = -0.28 p = 0.78	-0.07
	ECHOg vs Echo	1.14 (-0.09, 2.37)	t = 1.82 p = 0.068	-0.02	0.02 (-2.01, 2.05)	t = 0.02 p = 0.98	0.01
<b>DASS</b>	Overall ECHO vs TAU	-	-	-	1.64 (-7.25, 10.5)	t = 0.36 p = 0.72	0.07
	ECHOg vs Echo	-	-	-	0.26 (-0.24, 0.76)	t = 1.01 p = 0.31	0.23
	ECHOg vs Echo	-	-	-	-	-	-
<b>AES</b>	Overall ECHO vs TAU	-4.10 (-11.1, 2.91)	t = -1.15 p = 0.25	-0.19	-	-	-
	ECHOg vs Echo	-2.89 (-10.3, 4.49)	t = -0.77 p = 0.44	-0.13	-	-	-
	ECHOg vs Echo	-	-	-	-	-	-

<b>EE-FQ</b>	Overall ECHO vs TAU	-3.28, 2.46	t = -0.28 p = 0.78	-0.04	-	-	-
	ECHOg vs Echo	-2.61 (-5.78, 0.55)	t = -1.62 p = 0.11	-0.27	-	-	-

Patient Outcomes		6 months			12 months		
		Mean group difference (95% CI)	Test	Standardised Coefficient <sup>‡</sup>	Mean group difference (95% CI)	Test	Standardised Coefficient <sup>‡</sup>
<b>SEED / ANTSI</b>	Overall ECHO vs TAU	0.04 (-0.20, 0.28)	t = 0.34 p = 0.73	0.07	0.15 (-0.08, 0.39)	t = 1.27 p = 0.20	0.26
	ECHOg vs Echo	0.17 (-0.12, 0.45)	t = 1.18 p = 0.24	0.28	0.057 (-0.22, 0.35)	t = 0.40 p = 0.69	0.10
<b>BMI</b>	Overall ECHO vs TAU	0.4 (-0.43, 1.23)	t = 0.95 p = 0.34	0.18	(-0.47, 1.24)	t = 0.90 p = 0.37	0.17
	ECHOg vs Echo	-0.97 (-1.95, 0.02)	t = -1.95 p = 0.054	-0.44	-0.77 (-1.78, 0.23)	t = -1.52 p = 0.13	-0.35
<b>% wt./ht</b>	Overall ECHO vs TAU	1.50 (-2.79, 5.80)	t = 0.70 p = 0.49	0.13	1.44 (-2.73, 5.62)	t = 0.69 p = 0.49	0.13
	ECHOg vs Echo	-5.41 (-10.4, -0.42)	t = -2.15 p = 0.034	-0.48	-4.14 (-8.92, 0.65)	t = -1.72 p = 0.089	-0.37
<b>DASS</b>	Overall ECHO vs TAU	10.3 (-2.51, 23.1)	t = 1.61 p = 0.113	0.33	5.86 (-6.84, 18.6)	t = 0.92 p = 0.36	0.19
	ECHOg vs Echo	-7.14 (-20.2, 5.96)	t = -1.09 p = 0.281	-0.23	-3.01 (-17.0, 10.9)	t = -0.261 p = 0.79	-0.10
<b>DAWBA – Peer</b>	Overall ECHO vs	-	-	-	-0.81	t = -2.26	-0.36

<b>problems</b>	TAU				(-1.52, -0.10)	p = 0.027	
	ECHOg vs Echo	-	-	-	-0.28	t = -0.65	-0.13
					(-1.12, 0.57)	p = 0.52	
<b>DAWBA – Prosocial behaviour</b>	Overall ECHO vs TAU	-	-	-	1.16	t = 3.04	0.51
					(0.40, 1.92)	p = 0.003	
	ECHOg vs Echo	-	-	-	-0.63	t = -1.43	-0.21
					(-1.50, 0.25)	p = 0.16	
<b>CIA</b>	Overall ECHO vs TAU	-	-	-	2.04	t = 0.69	0.18
					(-3.83, 7.91)	p = 0.49	
	ECHOg vs Echo	-	-	-	-0.91	t = -0.27	-0.08
					(-7.49, 5.67)	p = 0.79	

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‡ - standardised coefficients were derived from dividing estimated difference by the standard deviation of the outcome variable at baseline.

‡‡ standardized coefficients derived from pooled SD of outcome (no baseline measure).

Abbreviations: TAU – Treatment as Usual; ECHO – Echo intervention; ECHOg – Echo Intervention with guidance Overall ECHO – ECHO and ECHOg combined;

Carers: DASS – Depression, Anxiety and Stress Scale; AESED – Accommodation and Enabling Scale for Eating Disorders; EE - FQ – Expressed Emotion Family Quotient; CASK – Carer Skills; Patients: SEED - Short Evaluation of Eating Disorders, BMI Body Mass Index; % *wt./ht* - Age adjusted weight for height; Bed days Number of days as inpatient; Hours of service use – number of hours engaged with health services; DASS – Depression, Stress and Anxiety Scale; DAWBA - Development and Well-being Assessment ; CIA – Clinical Impairment Assessment



Figure 1. Consort diagram for the trial.

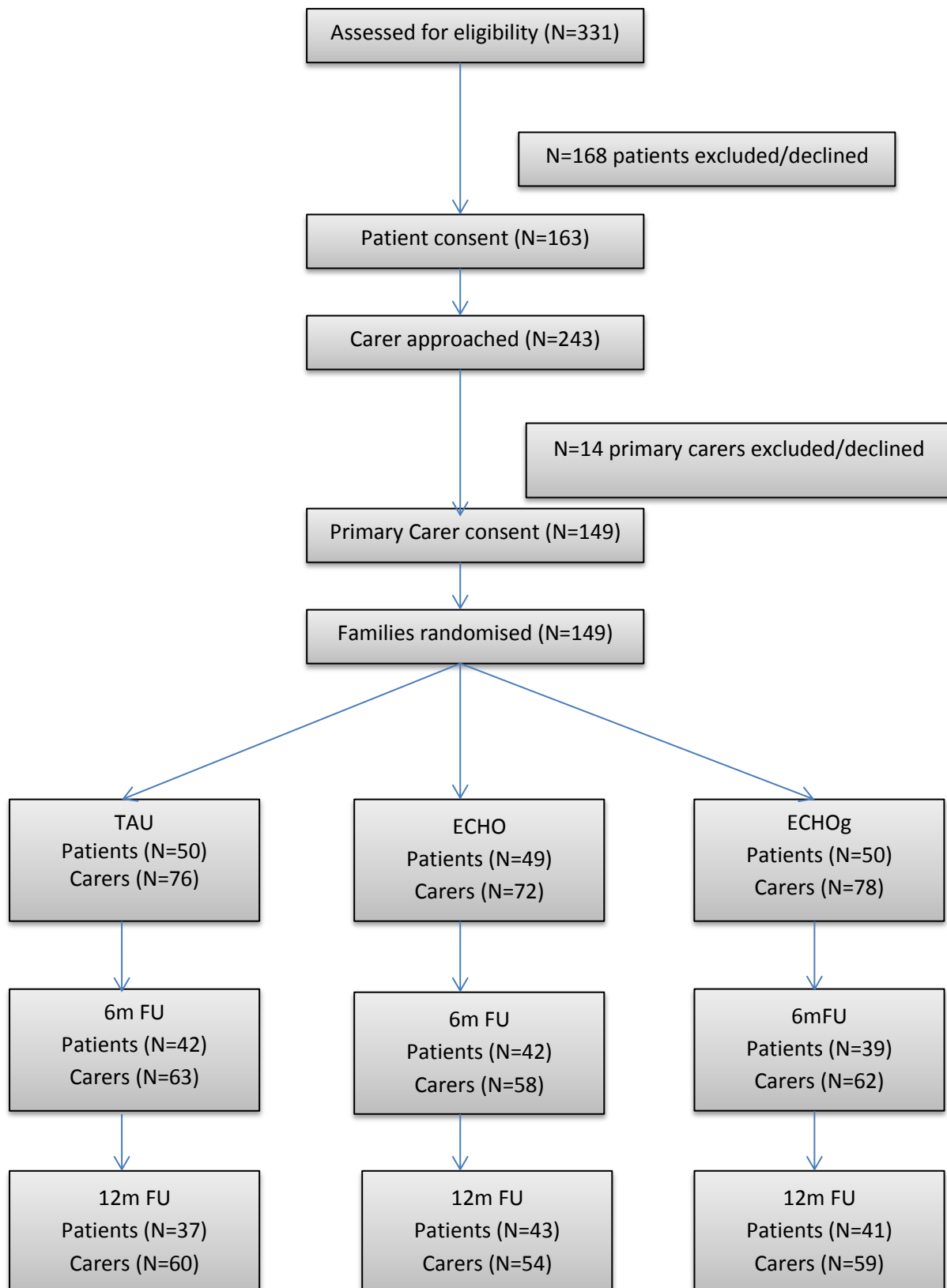


Figure 2 BMI score for patients over time from 0 to 12 months according to the 3 treatment groups (ECHO, ECHO with guidance (ECHOg) and Treatment as Usual (TAU) ). Means and 95 % confidence intervals are based on 100 rounds of multiple imputation.

